



CANCERcare®

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# fact sheet

## COPING WITH MYELODYSPLASTIC SYNDROMES

A diagnosis of myelodysplastic syndromes (MDS) can leave you and your loved ones feeling uncertain, anxious and overwhelmed. There are important treatment decisions to make, emotional concerns to manage, and insurance and financial paperwork to organize, among other practical concerns.

It is helpful to keep in mind that there are many sources of information and support for people coping with MDS. By learning about this diagnosis and its treatment options, communicating with your health care team, and surrounding yourself with a support network, you will be better able to manage your MDS and experience a better quality of life.

### UNDERSTANDING YOUR DIAGNOSIS AND TREATMENT PLAN

Myelodysplastic syndromes (MDS) occur when the blood-forming cells in the bone marrow are damaged and the production of blood cells is interrupted.

There are a wide range of treatments for MDS, including chemotherapy, stem cell transplant and supportive therapy. If treatment is necessary, ask your health care team to recommend reliable publications and websites to learn more. Knowing what to expect can help you feel more in control.



### THE IMPORTANCE OF COMMUNICATING WITH YOUR HEALTH CARE TEAM

Because MDS are a complex condition with complex treatment options, good communication between you and your health care team is key. Your oncologist, nurses, and other members of your health care team work together to treat your MDS. Since medical appointments are the main time you will interact with your team, being as prepared as possible for these visits is important. It will help ensure that you understand your diagnosis and treatment, get answers to your questions, and feel more satisfied with your overall care. Read CancerCare's fact sheet, "Doctor, Can We Talk?": Tips for Communicating With Your Health Care Team," to learn how you can communicate more effectively with your health care team.

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## Financial Assistance

There are many organizations that provide help with medical billing, insurance coverage, and reimbursement issues. There is also financial assistance available to help people who cannot afford the cost of their medications. Good places to start your research are the websites of the Cancer Financial Assistance Coalition ([www.cancerfac.org](http://www.cancerfac.org)) and the Partnership for Prescription Assistance ([www.pparx.org](http://www.pparx.org)).

## Benefits and Entitlements

Local and county government agencies can give you information on Social Security, state disability, Medicaid, income maintenance, the Low Income Heating Energy Assistance Program (LIHEAP), and food stamps. Check your local phone directory for listings.

## Housing/Lodging

The Hope Lodge of the American Cancer Society, the National Association of Hospital Hospitality Houses ([www.nahhh.org](http://www.nahhh.org)), and other organizations provide temporary lodging for families of a patient who needs to travel far from their home for treatment. Joe's House is a nonprofit organization that offers an online database with lodging information near cancer treatment centers across the U.S. To learn more, visit [www.joeshouse.org](http://www.joeshouse.org).

## GETTING EMOTIONAL SUPPORT

Adjusting to and finding ways to cope with MDS is an important part of healing, along with treatment. There are many organizations, such as CancerCare, that provide support services to help people affected by cancer. Individual counseling is available to help you learn ways to cope with the emotions and challenges raised by your diagnosis. Support groups can connect you with other patients in a safe, supportive environment. Cancer affects the whole person and their loved ones, so it's important to create a support network as part of managing your care.



## CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers and world-leading cancer experts.

To learn more, visit [www.cancercare.org](http://www.cancercare.org) or call **800-813-HOPE (4673)**.

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